USING e-ANNOTATION TOOLS FOR ELECTRONIC PROOF CORRECTION

Required software to e-Annotate PDFs: Adobe Acrobat Professional or Adobe Reader (version 11 or above). (Note that this document uses screenshots from Adobe Reader DC.) The latest version of Acrobat Reader can be downloaded for free at: http://get.adobe.com/reader/

Once you have Acrobat Reader open on your computer, click on the Comment tab (right-hand panel or under the Tools menu).

This will open up a ribbon panel at the top of the document. Using a tool will place a comment in the right-hand panel. The tools you will use for annotating your proof are shown below:

1. **Replace (Ins) Tool – for replacing text.**
   - Strikes a line through text and opens up a text box where replacement text can be entered.
   - How to use it:
     - Highlight a word or sentence.
     - Click on the replace tool.
     - Type the replacement text into the blue box that appears.

2. **Strikethrough (Del) Tool – for deleting text.**
   - Strikes a red line through text that is to be deleted.
   - How to use it:
     - Highlight a word or sentence.
     - Click on the strikethrough tool.
     - The text will be struck out in red.

3. **Commenting Tool – for highlighting a section to be changed to bold or italic or for general comments.**
   - Use these 2 tools to highlight the text where a comment is then made.
   - How to use it:
     - Click on the tool.
     - Click and drag over the text you need to highlight for the comment you will add.
     - Click on the tool.
     - Click close to the text you just highlighted.
     - Type any instructions regarding the text to be altered into the box that appears.

4. **Insert Tool – for inserting missing text at specific points in the text.**
   - Marks an insertion point in the text and opens up a text box where comments can be entered.
   - How to use it:
     - Click on the insert tool.
     - Click at the point in the proof where the comment should be inserted.
     - Type the comment into the box that appears.

Experimental data is available for ORFs to be had to meet all of the following criteria:

2. Absence of similarity to known proteins.
3. Absence of functional data which could n the real overlapping gene.
4. Greater than 25% overlap at the N-terminus with another coding feature; cDNA both ends; or ORF containing a tRNA.
5. **Attach File Tool** – for inserting large amounts of text or replacement figures.

- Inserts an icon linking to the attached file in the appropriate place in the text.

**How to use it:**
- Click on 
- Click on the proof to where you’d like the attached file to be linked.
- Select the file to be attached from your computer or network.
- Select the colour and type of icon that will appear in the proof. Click OK.

The attachment appears in the right-hand panel.

6. **Add stamp Tool** – for approving a proof if no corrections are required.

- Inserts a selected stamp onto an appropriate place in the proof.

**How to use it:**
- Click on 
- Select the stamp you want to use. (The Approved stamp is usually available directly in the menu that appears. Others are shown under Dynamic, Sign Here, Standard Business).
- Fill in any details and then click on the proof where you’d like the stamp to appear. (Where a proof is to be approved as it is, this would normally be on the first page).

7. **Drawing Markups Tools** – for drawing shapes, lines, and freeform annotations on proofs and commenting on these marks.

- Allows shapes, lines, and freeform annotations to be drawn on proofs and for comments to be made on these marks.

**How to use it:**
- Click on one of the shapes in the Drawing Markups section.
- Click on the proof at the relevant point and draw the selected shape with the cursor.
- To add a comment to the drawn shape, right-click on shape and select Open Pop-Up Note.
- Type any text in the red box that appears.

For further information on how to annotate proofs, click on the Help menu to reveal a list of further options:
Dear Author,

During the copyediting of your manuscript, the following queries arose.

Please refer to the query reference callout numbers in the page proofs and respond to each by marking the necessary comments using the PDF annotation tools.

Please remember illegible or unclear comments and corrections may delay publication.

Many thanks for your assistance.

**AUTHOR**: Please note that missing content in references have been updated where we have been able to match the missing elements without ambiguity against a standard citation database, to meet the reference style requirements of the journal. It is your responsibility to check and ensure that all listed references are complete and accurate.

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10  AUTHOR: ‘through the U13 funding grant, a cooperative conference grant between the Cancer and Aging Research Group in collaboration with the Geriatrics and Clinical Gerontology branch of the National Institute on Aging and the National Cancer Institute’ correct as set?

11  AUTHOR: Possible to provide a reference citation for the quote beginning ‘to provide a forum for a multidisciplinary team of investigators in geriatrics and oncology...’?

12  AUTHOR: Possible to provide date for Ms. Finch’s communication regarding Figure 2?

13  AUTHOR: Please check all financial footnotes carefully.

14  AUTHOR: Ref. 1 correct as set? Please provide year of publication or website address and date it was last accessed by you.

15  AUTHOR: Ref. 11 correct as set?

16  AUTHOR: Ref. 14 correct as set? Unable to verify.

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Please confirm that the funding sponsor list below was correctly extracted from your article: that it includes all funders and that the text has been matched to the correct FundRef Registry organization names. If a name was not found in the FundRef registry, it may not be the canonical name form, it may be a program name rather than an organization name, or it may be an organization not yet included in FundRef Registry. If you know of another name form or a parent organization name for a “not found” item on this list below, please share that information.

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<td>National Cancer Institute</td>
<td>National Cancer Institute</td>
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Commentary

Engaging Older Patients With Cancer and Their Caregivers as Partners in Cancer Research

Nikesha J. Gilmore, PhD 1; Beverly Canin, BS 2; Mary Whitehead, BFA 2; Margaret Sedenquist, BS 2; Lorraine Griggs, BS 2; Lynn Finch, BS 2; Valerie Grossman, RN 1 2; Valerie Targia, BAsc 2; Megan Wells, MPH 1; Charles Kamen, PhD 1 3; Marie Flannery, PhD, RN 1; Allison Magnuson, DO 1; Sandy Plumb, BS 1; Spencer Obrecht, MS 1; Lisa M. Lowenstein, PhD, MPH 1 3; Gilberto Lopez, ScD, MPH 1; Jainy Anderson, BS 1; Jeffrey Berenberg, MD 4; Victor Vogel, MD 5; James Bearden, MD 6; William Dale, MD, PhD 7; and Supriya G. Mohile, MD, MS 1

INTRODUCTION

Active engagement of stakeholder partners (patients, family members, caregivers, and organizations that are representative of the population of interest in a study), as defined by the Patient-Centered Outcomes Research Institute (PCORI), 1 has been increasingly regarded as an essential component of research, in which stakeholder experiences and perspectives can thoroughly guide and inform research processes. 2-4 The participation of stakeholder partners in clinical research makes research more meaningful and relevant, increases the generalizability and attractiveness of research findings to patients and clinicians, and aids in the translation of research findings into clinical practice. 3,5-8 Partner engagement is mutually beneficial to partners and researchers. Patient partners have reported feelings of empowerment and value, a sense of cohesiveness, and having a better understanding of research, which collectively resulted in positive attitudes toward clinical research. 9 Researchers described having a greater understanding of patients’ needs after engaging with patient partners, thereby bringing new insights into their research. 6,9 Actively engaging stakeholder partners in clinical research should be an essential component of research planning.

Engaging patient partners in clinical research has been shown to be feasible and to have a variety of positive outcomes. 10 However, in geriatric oncology research, specific mechanisms and the logistics of assembling a patient and caregiver partner stakeholder group that is mutually beneficial to both the research team and the stakeholder group to the best of our knowledge has not yet been thoroughly explored. Herein, we described our patient partner engagement in study optimization, shape, conduct, and the dissemination of research findings using PCORI’s 6 principles as a guide: 1) reciprocal relationships; 2) co-learning; 3) partnerships; 4) transparency; 5) honesty; and 6) trust. 4 We also have described the mutually beneficial effect of patient and caregiver partner engagement among all individuals involved in the study processes and how this engagement shaped future attitudes toward research. Active partner engagement laid a foundation that was pivotal to the success of the Communicating About Aging and Cancer Health (COACH) clinical trial. 11

Patient and Caregiver Partners and the COACH Study

Older patients with cancer have been underrepresented in oncology clinical trials due to exclusion based on chronological age and the presence of aging-related conditions (eg, chronic diseases, disabilities, and cognitive problems), thereby bringing new insights into their research. 6,9 Actively engaging stakeholder partners in clinical research should be an essential component of research planning.

We graciously thank all Stakeholders for Care in Oncology and Research for our Elders board (SCOREboard) members for their valuable contributions that resulted in the profound success of the Communicating About Aging and Cancer Health (COACH) trial. SCOREboard members include Beverly Canin (chair), Mary Whitehead, Margaret Sedenquist, Lorraine Griggs, Lynn Finch, John Aarne, Valerie Targia, Robert Harrison, Valerie Aarne, Dorothy Dobson, Jacquelyn Dobson, Burt Court, Polly Hudson, and Ray Hutchins. We also thank the patients and caregivers who participated in the COACH trial as well as the research staff in the University of Rochester National Cancer Institute Community Oncology Research Base network.

This article is dedicated to the memory of SCOREboard members Ray Hutchins and Robert Harrison.

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thus limiting the available data regarding the safety and efficacy of cancer treatment in older adults. In 2012, a team of geriatric oncology researchers, led by Supriya G. Mohile, MD, MS, as the principal investigator (PI), received PCORI funding to conduct what to our knowledge is the largest randomized geriatric assessment (GA) clinical trial performed to date: the COACH trial. The GA is a validated, multidimensional tool that evaluates aging-related domains (eg, functional status and cognition), and is recommended for the identification of vulnerabilities not found by commonly used oncology tools when treating patients aged ≥65 years who are undergoing chemotherapy. The COACH trial demonstrated that providing a summary of the GA as well as GA-guided recommendations to oncologists, patients, and their caregivers improved communication regarding aging-related concerns. In addition, the COACH trial demonstrated that it is possible to enroll vulnerable older adults with advanced cancer in a clinical trial, thus providing additional evidence that individuals should not be excluded from oncology clinical trials because of age. The success of this trial has been attributed largely to the active engagement of the patient and caregiver partner group from study inception to completion.

Development of the Patient, Caregiver, and Advocate Stakeholder Group

PCORI emphasizes rigorous patient-driven research through active partner engagement. Following PCORI’s recommendations, the first such patient partner (patient, caregiver, and advocate) stakeholder group in geriatric oncology, Stakeholders for Care in Oncology and Research for our Elders board (SCOREboard), was formed with the mission to “provide feedback and make recommendations to the University of Rochester PCORI-funded research team based on the knowledge and personal experiences of SCOREboard members in order to elevate the medical care, support services, and outcomes for patients 65 and older with cancer and their caregivers.”

SCOREboard was a purposefully designed diverse group that used the inherent skills and personal cancer experiences of its members to guide the research team toward the completion of a successful clinical trial. SCOREboard members represented a wide range of races and ethnicities, educational and employment backgrounds, patient advocate experiences, cancer types, cancer histories, and geographic locations. In addition, SCOREboard members directly reflected the COACH study population. Members were either 1) an older patient (patient aged ≥65 years who currently was in treatment for cancer of any stage); 2) a caregiver (caregiver of a patient aged ≥65 years who was receiving treatment for cancer); and/or 3) a patient advocate (a person, cancer survivor, or patient currently undergoing cancer treatment with demonstrated experience in cancer support, education, or research advocacy).

During the study design stage, the first step in developing SCOREboard was the recruitment of Beverly Canin, BS, an experienced patient advocate member of the Cancer and Aging Research Group (CARG), a national group of investigators, clinicians, and other providers interested in geriatric oncology research. Ms. Canin worked with the research team to design the patient/caregiver advisory group included in the initial grant proposal submitted to PCORI (Fig. 1) and agreed to chair the group, which subsequently was named “SCOREboard.” The design included methods to recruit the proposed patient/caregiver advocacy population and the roles at each stage of the study. The PCORI budget proposal included funding for consultation fees and/or stipends. An amount was decided through discussions with the SCOREboard chair that reasonably compensated SCOREboard members.

After the PCORI grant was awarded, recruitment procedures for SCOREboard members were activated using clear guidelines for candidate qualifications as well as descriptions of tasks and responsibilities. Potential SCOREboard members, who had various backgrounds as patients and/or in clinical research, advocacy, and health literacy, were recommended by CARG clinician researchers who identified potential patients, caregivers, or advocates from their practices or by coordinators of patient and family advisory boards at CARG member institutions. Candidates completed written applications that described the goal of the COACH trial and the mission of SCOREboard. The application also contained specific questions regarding previous patient advocate experience and whether the individual was a patient with cancer, a caregiver of a patient with cancer, or a survivor, including their motivations for joining SCOREboard. The SCOREboard chair and PI interviewed applicant board members to ensure that, in addition to being an older patient, caregiver, and/or patient advocate, they had 1) a passion for enhancing the care experience of others, 2) the ability to recognize problems, 3) the motivation to focus energies toward solutions and/or improved services, 4) good listening and communication skills, 5) respect for diverse perspectives, 6) the ability to speak comfortably and candidly in a group, and 7) the ability to participate in regular monthly meetings as well as various committees or projects with varying time commitments.
SCOREboard began with 14 members who ranged in age from 55 to 87 years and represented different careers (1 artist, 3 business professionals, 1 teacher, 1 nurse, 2 social workers, 2 administrative assistants, 2 nonprofit administrators, and 1 youth service professional). Many SCOREboard members fit >1 stakeholder category: 1 patient, 4 caregivers, 4 patient/advocates, 3 patient/caregivers, and 2 patient/caregivers/advocates. Each SCOREboard member signed a letter of agreement, which delineated the responsibilities of both SCOREboard members and the research team. SCOREboard members committed to attending virtual meetings; completing assignments; sharing knowledge, experience, and talents; and maintaining the confidentiality of the study information. The research team committed to providing biannual stipends, providing any assistance necessary to ensure that SCOREboard...
members were effectively engaged, and maintaining the confidentiality of the board members.

**Partners in Protocol Development and the Study Start-Up Process**

A thoroughly planned study start-up (through the demonstration of the patient partner engagement principles of reciprocal relationships, which include transparency, honesty, and trust) paved the way for the successful completion of the COACH trial. To accomplish SCOREboard’s mission, engagement was facilitated via regular virtual web-based meetings, which enabled all members to contribute equally toward the board’s mission. In addition, the research team had a dedicated administrator, who reported to both the study PI and SCOREboard chair, and assisted with technical difficulties by preparing instructions, troubleshooting technical difficulties, and providing any necessary equipment.

Keys to the success of the partnership with SCOREboard were as follows:

1. An effective SCOREboard mission statement;
2. A group acronym, developed by the group, that members could identify with;
3. Comprehensive educational materials about the project;
4. Regular SCOREboard monthly/bimonthly meetings, including the PI and/or other members of the research team, scheduled well in advance;
5. Flexibility to adjust meeting formats and materials to accommodate the needs of the group;
6. Formal agendas and tasks effectively communicated to the group (e.g., “homework” assignments);
7. Provision of adequate time to review, provide feedback, and discuss projects;
8. Meetings facilitated by the SCOREboard chair;
9. The collaborative authenticity of the PI and research team; and
10. Research team administrative staff available for recordkeeping and assistance in facilitating all SCOREboard-related activities.

For the success of the COACH trial, it was essential that the researchers’ goals of addressing scientific questions were effectively aligned with the preferences of patients and caregivers. This alignment was evident in materials developed by SCOREboard to aid clinical research associates with study participant recruitment. These materials explained the study’s importance in an empathetic manner that considered patients’ and family members’ emotional well-being during the difficulties of the cancer journey. The materials were visually appealing, concise, patient-friendly, and written at a sixth-grade to eighth-grade reading level. They adequately explained the study, as well as participants’ risks and benefits (Table 1). Some of the factors SCOREboard considered while advising the research team and developing study-related materials are outlined below.

**Language.** The use of appropriate language and the critical importance of authentic communication among all stakeholder groups was considered by SCOREboard. It was important to deliberate on word use such as “elderly” and “geriatric,” which some older adults find off-putting or offensive, and to develop alternative ways of designating the study population. Other factors considered were patients’ general literacy level and medical understanding as well as potential cultural influences and/or biases.

**Developing and fostering trust between potential patient and caregiver partners and the research team.** It was important to understand how to break through the mistrust and fears that patients might be harboring by determining past causes of mistrust. Ways to do this included establishing gentler mechanisms of communication from clinical staff to help potential participants feel more at ease about enrolling in the clinical trial, assuring potential participants that their information would be kept confidential, and explaining how data obtained could help future patients.

**Creating simple and clear study aids.** Messages were to be kept accurate, simple, and limited to what is needed to aid a patient in deciding whether or not to participate. Study aids should not overwhelm patients by containing too much information; the use of “medical or institutional” terminologies should be minimal.

“**Persuade**” rather than “sell” the study. We sought to humanize all forms of communication and ensure that caution is used when “pitching” the study to potential participants.

**Partners in Study Implementation and Continuation**

It was anticipated that study participant recruitment would be difficult due to the frailty of the study population, but initial recruitment was even slower than expected. SCOREboard members, together with the
TABLE 1. Examples of How Collaborating With SCOREboard Enhanced the Quality of the COACH Study Through the Development of Documents, Study Aids, and Other Tools

<table>
<thead>
<tr>
<th>SCOREboard Assignment</th>
<th>SCOREboard’s Effort and Feedback</th>
<th>Final Product</th>
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<tbody>
<tr>
<td>Patient partner group name</td>
<td>Develop a name that depicts the values of the patient partner group</td>
<td>Initial name, “Stakeholders for Care in Oncology and Research for the Elderly Board,” was rejected</td>
</tr>
<tr>
<td>COACH logo</td>
<td>Work with the Strong Memorial Hospital (Rochester, NY) art department to develop a logo to symbolize the mission of the study</td>
<td>“Elderly” has a negative association</td>
</tr>
<tr>
<td>Recruitment brochure</td>
<td>Design a patient-friendly brochure to introduce this study to a patient</td>
<td>Initial design included a megaphone, which suggests yelling rather than communication</td>
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<tr>
<td>Study documents</td>
<td>Review documents for completeness and usability</td>
<td>Image should represent 3-way communication between patient, caregiver, and physician</td>
</tr>
<tr>
<td>Communication tools</td>
<td>Develop a tool to be used by research associates who were recruiting participants onto the COACH study</td>
<td>Different graphics and color combinations were suggested</td>
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<tr>
<td>Dissemination discussions</td>
<td>Develop dissemination plans so that the results of the study could be shared with varying target audiences</td>
<td>Updated language of each section so that participants’ responsibilities, study goals, and importance were defined clearly</td>
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Abbreviations: AARP, formerly the American Association of Retired Persons; ACS, American Cancer Society; CARG, Cancer and Aging Research Group; COACH, Communicating About Aging and Cancer Health; NCBI, National Center for Biotechnology Information; NCORP, National Cancer Institute Community Oncology Research Program; SCOREboard, Stakeholders for Care in Oncology and Research for our Elders board; SSRN, Social Science Research Network.

research team and other stakeholders, evaluated study procedures and study-related documents to identify unforeseen recruitment barriers. Consequently, the study was optimized by the modification of eligibility criteria and the streamlining of study-related documents to reduce burden to participants and study personnel. These
Partners in Study Closeout, Analysis, and Dissemination

Active partner engagement required effective co-learning and partnership strategies. SCOREboard members had limited clinical research experience and therefore substantial time was dedicated to the educational components of engagement procedures (eg, descriptions of research processes including the gathering of pilot data, applying for funding, and institutional review board activities). This educational opportunity allowed SCOREboard members to feel more empowered and engaged throughout the study. As the study neared completion, many opportunities arose to conduct secondary analyses on collected data. The research team reviewed the overall themes of data collected as part of the COACH trial with SCOREboard. Members then ranked themes according to what they thought could be most beneficial to older patients with cancer and their caregivers. These analyses then were prioritized by the research team. Throughout this process, it was determined that the emotional toll of caring for older patients with advanced cancer was a major concern and a secondary analysis of data from the COACH trial regarding this topic was presented at the 2017 International Society of Geriatric Oncology Annual Conference. SCOREboard also provided editorial assistance for the resulting article.14 SCOREboard members also were given the opportunity to serve as coauthors, contributing to the intellectual content, writing, and/or reviewing of 10 abstracts and/or articles based on data from the COACH trial.

In a parallel effort, the PI of the COACH trial, along with other CARG leaders (William Dale, MD, PhD, and Arti Hurria, MD), received a cooperative conference grant for CARG to host the Geriatric Oncology Research to Improve Clinical Care conferences in 2010, 2012, and 2015 through the U13 grant, a cooperative conference grant between the Cancer and Aging Research Group in collaboration with the Geriatrics and Clinical Gerontology branch of the National Institute on Aging and the National Cancer Institute. The overarching mission of the conferences was “to provide a forum for a multidisciplinary team of investigators in geriatrics and oncology to review the present level of evidence in geriatric oncology, identify areas of highest research priority, and develop research approaches to improve clinical care for older adults with cancer within the next ten years.” Seven SCOREboard members were funded by the U13 grant to attend the 2015 conference entitled “Design and Implementation of Intervention Studies to Maintain or Improve the Quality of Survival of Older and/or Frail Adults with Cancer” and served as coauthors on 7 articles.15-21 At this meeting, SCOREboard members also helped to guide future research priorities in the field of geriatric oncology.

In the final year of the COACH trial, a significant amount of SCOREboard’s effort was dedicated to the discussion of dissemination plans (Table 1). The discussions focused on ways to ensure that the findings reached and influenced the appropriate target audiences, including contributing researchers, trial participants, geriatric oncology health care providers, older patients with advanced cancer and their caregivers,
patient advocacy groups, and organizations that provide services to older patients with cancer. A SCOREboard member, Lynn Finch, BS, created images to be used in dissemination materials in the future. These images were aimed at stimulating conversations between the oncologists, patients, and patient caregivers regarding aging-related concerns. Ms. Finch stated: “I envision the imagery and the ‘essential question’ posed in the samples as a poster or cover of a flyer in which we would also encourage patients to: ‘Ask your doctor about a GA’ then go on to better explain what a GA entails and what research has revealed about the efficacy of its use in standardized cancer care” (written communication, date) (Fig. 2).

**Challenges in Active Engagement**

Effectively engaging patient partners requires a significant amount of time. Given the tight timeline between receiving funding and enrolling the first patient, and the fact that SCOREboard members were recruited after the receipt of grant funding (with the exception of the SCOREboard chair), the research team was not able to fully incorporate all recommendations from SCOREboard before the study began. We recommend, if feasible, that stakeholder groups be fully formed during the design phase, well before the receipt of study funds. The development of a successful stakeholder group requires efficient coordination between the study team, board members, and external groups (eg, regulatory bodies and clinical sites) (Fig. 1B). Therefore, it is beneficial to have a research team staff member (≥50% effort) dedicated to managing all aspects of engaging SCOREboard as well as their interactions with other constituents of the stakeholder group (Fig. 1).

Given that greater than one-half of the members of SCOREboard had no prior advocacy experience and the majority of members were from non-science backgrounds, the research team was challenged to ensure that all members felt empowered to have their voices heard. SCOREboard’s chair and the study PI actively engaged with all members during group and 1-on-1 telephone calls to ensure that all members were able to provide equal input and felt they were a valued member of the team. Members reported that in-person meetings once or twice a year would have assisted in fostering a team environment. Solely relying on technology for the meetings was challenging, and members found technological problems to be disruptive and frustrating at times. In addition, members found it difficult to retain the vast amount of information shared during meetings, and this sometimes led to feelings of a lack of preparation and disempowerment. Members felt that maintaining monthly meetings, with detailed agendas sent in advance of each meeting that included specific questions for SCOREboard to answer, aided in the learning process and boosted the group’s vitality.

Additional challenges arise when working with nonresearch members on a clinical trial. Confidentiality and other regulations limit communication mechanisms between patient partners and study staff and participants. Intriguingly, this limitation provided SCOREboard with the unique opportunity for creative thinking. SCOREboard developed innovative communication practice mechanisms with oncologists and research associates to assist them in communicating about the study when recruiting potential participants. Special webinars were held in which SCOREboard members role-played potential participants. Scripted dialogues also were developed with empathetic phrases designed to aid members of the clinical team who were recruiting potential participants at various stages of their cancer journey (Table 1).
Effect of Active Engagement on SCOREboard Members and Valuable Takeaways

Puts et al.\textsuperscript{7} summarized the benefits experienced by partners who were actively engaged in clinical research. Potential benefits include feelings of empowerment and value and changed attitudes toward clinical research.\textsuperscript{7} As the COACH trial drew to a close, a special meeting was conducted to allow members to reflect on their experience and provide feedback regarding barriers to and facilitators of engaging with the research team. SCOREboard members experienced benefits similar to those reported in the study by Puts et al.\textsuperscript{7} and found that participation in SCOREboard was a positive educational experience (Table 2). By the end of the study, members had a broader understanding of clinical trials and the research process, not just as the final option for patients with advanced disease, but also as a mechanism with which to expand our knowledge of how to better prevent and/or treat diseases and improve quality of life. Members learned to appreciate the intricacies involved in the design and implementation of a clinical trial as well as the varying roles played by different entities, such as funding agencies, participants, researchers, and stakeholders.

One of the meetings toward the end of the study included time for specific reflections by SCOREboard members concerning their experiences throughout the study. Members reported that they were enthusiastic about engaging in the COACH trial as partners, but many recalled feeling a reluctance about participating in any clinical trial. The reluctance largely was due to a misunderstanding of the purpose of research and a distrust of the researchers’ agendas (Table 2). This emphasizes the need for patient education as part of the clinical trial recruitment process, which can be achieved by incorporating patient and caregiver partner groups from the early design phase of research studies, at which time partners can aid researchers in destigmatizing the role of patients in clinical trials. As a direct result of being in SCOREboard, all members reported that given the opportunity, they would participate in other stakeholder groups as partners. In addition, SCOREboard members who reported an initial reluctance to participate in a clinical trial stated that they were more likely to be a trial participant if approached. Members reported feeling increased confidence in asking questions about the nature of the research, as well as their responsibilities and associated risks due to participation in a clinical trial.

Due to the quality and quantity of interactions in active engagement, SCOREboard members developed lasting friendships and built a community that provided emotional support and guidance to each other as they traveled through their individual cancer journeys. We have lost several members over the course of the COACH

### TABLE 2. Quotes From SCOREboard Members Concerning the Effects of Active Engagement

<table>
<thead>
<tr>
<th>Initial Reluctance to Participate in Clinical Trials and Changed Attitudes Quotes:</th>
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<tbody>
<tr>
<td>• “I refused when I was approached by someone who just asked me to be in a research study when I had cancer. After being a SCOREboard member and seeing the need for clinical trials, I definitely would become a participant.”</td>
</tr>
<tr>
<td>• “I’ve been highly critical of PIs who say they have patient advocates as collaborators or partners in their study, when they’ve really only been tokens. At times I wondered if it was even possible to establish real partnerships between researchers and patients/patient advocates. Now I know it is possible.”</td>
</tr>
<tr>
<td>• “I’ve learned of the reluctance of medical doctors to participate in research because of their time constraints, even though the research may be helpful to them in the long run. I particularly appreciate the fact that questions are raised about the efficacy of treatments and then research is conducted in a fair and honest manner to ascertain answers as clearly as possible.”</td>
</tr>
<tr>
<td>• “Before participating with SCOREboard, I had the stereotypical impression that clinical trials were conducted using only new or experimental drugs. I didn’t realize that the term ‘clinical trials’ could in fact be anything that enhances people’s lives.”</td>
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<th>Language and Communication in Study Quotes:</th>
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<td>• “The impact of language on the anticipated results was shown to be very important, as became evident in so many of the SCOREboard discussions. It was enlightening and rewarding to hear members of SCOREboard be so vehemently careful about the language that was to be used in the recruitment and in the study.”</td>
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<td>• “We had lengthy discussions about words—something I think was very valuable. To deliberate on simple words, such as ‘elderly,’ and to find new ways to designate the populations with whom we were trying to communicate; would ‘older’ or ‘senior’ or other words be a better way to address an older population? Did we need to establish a gentler way to communicate? To help our patient population feel more at ease for participating in the clinical trial?”</td>
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<td>• “I have had the impression that clinical trials are conducted using only new or experimental drugs. I didn’t realize that the term ‘clinical trials’ could in fact be anything that enhances people’s lives.”</td>
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<th>Takeaways/What Was Learned Quotes:</th>
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<td>• “I learned how clinical trials helped in the battle against cancer. Cancer patients and their caregivers should participate in clinical trials. It would be a good way to prove that a patient with a positive attitude has a much better chance of survival.”</td>
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<td>• “I am learning a great deal in several different areas. For instance, I did not know about the work required to recruit subjects for research. I did not know that people are hired and trained to recruit. It is also interesting the amount of care for the subjects that is included in the planning.”</td>
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<td>• “I learned something about the amount of work that is required in the preparation of a research project—how the interest of each of the stakeholders—patients, doctors, staff, funders, must be respected and honored.”</td>
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Abbreviations: NCI, National Cancer Institute; PCORI, Patient-Centered Outcomes Research Institute; PI, principal investigator; SCOREboard, Stakeholders for Care on Oncology and Research for our Elders board.

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trial. The camaraderie that exists between SCOREboard members assisted them, as well as the families of the deceased members, with the processing of the grief that accompanies loss. Recently, the field of geriatric oncology lost an inspirational leader, Dr. Arti Hurria, who was an essential member of the COACH research team. Her death has further inspired SCOREboard and the research team to continue their work, pushing the field of geriatric oncology forward to fulfill her ultimate mission of improving the care of older adults with cancer.

**Effect of Active Engagement on the Research Team and Valuable Takeaways**

SCOREboard's participation in the COACH trial forever shaped the way the COACH research team views clinical research. Efforts now are made to view each research proposal through the eyes of the study's patient population, who are the individuals with the most to gain from the study's outcomes. At the onset of every new research idea, the following questions are asked: 1) how does this impact the patient population; 2) what are the patients' preferences; and 3) are the questions framed in such a way that the average patient can understand? As a direct result of the tremendous benefits experienced after engaging with SCOREboard, all new research concepts proposed by the research team contain detailed input from SCOREboard. SCOREboard currently is funded through a National Institute on Aging R21/R33 phased innovation grant to develop a national infrastructure for cancer and aging research (William Dale, MD, PhD, Arti Hurria, MD, and Supriya G. Mohile, MD, MS). The positive outcomes of engaging with SCOREboard throughout the COACH trial was evidenced by researchers in the University of Rochester's internal and external networks. SCOREboard's input is highly requested by researchers at the University of Rochester Medical Center, and SCOREboard has aided researchers from that institution in grant applications for infrastructure funding mechanisms to advance research in the area of geriatric oncology (including the R21/R33 geriatric oncology infrastructure grant). 7 clinical trials focused on geriatric oncology, and 3 conferences to establish research priorities. Eight of these efforts received funding, and 3 are pending a funding decision.

**Conclusions**

The diversity of SCOREboard members, along with the communality of the mission, fostered the development of special friendships, which served as the backdrop on which the successful outcomes of engagement with SCOREboard were built. Actively engaging SCOREboard allowed for the successful completion of a clinical trial that was widely accepted and performed in community oncology sites throughout the United States. Furthermore, SCOREboard engagement, along with positive interactions with other stakeholders in the COACH trial, led to what to our knowledge is the first study to demonstrate the ability of a GA intervention to positively change the behavior of oncology providers and increase communication and satisfaction with communication between patients and caregivers and their oncologists regarding aging-related concerns. In addition to SCOREboard engagement having positive effects on study outcomes, this engagement encouraged members to feel empowered due to changed attitudes regarding clinical research. The success of this interaction requires the following elements: 1) a highly engaged PI who is committed to including the perspectives of patients and their caregivers; 2) an empowered and active patient partner chair with past experience in patient advocacy; 3) a research team member on the staff who is dedicated to partner engagement activities; 4) funding for in-person meetings and to ensure that partners are adequately compensated for their time; 5) clearly defined roles for partners; and 6) opportunities for additional engagement activities.

**FUNDING SUPPORT**

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**CONFLICT OF INTEREST DISCLOSURES**

Marie Flannery has received grants from the National Cancer Institute (NCI) of the National Institutes of Health (grants UG1CA189961 and NCI R25 CA102618) for work performed as part of the current study. Jeffrey Berenberg and James Bearden have received NCI Community Oncology Research Program grants for work performed as part of the current study. The other authors made no disclosures.

**REFERENCES**

Active patient partner engagement with Stakeholders for Care in Oncology and Research for our Elders board (SCOREboard) (a diverse group of older patients with cancer, caregivers of older patients with cancer, survivors, and patient advocates) to conduct what to the authors’ knowledge is the largest randomized geriatric assessment clinical trial published to date has been shown to be feasible and to result in tangible and invaluable benefits for both the research team and patient partners alike. Actively engaging patient partners should be an essential component of the development, conduct, and completion of all clinical research.
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